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Prevalence, goals of care and long-term outcomes of patients with life-limiting illness referred to a tertiary ICU

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ABSTRACT

Objective: To describe the prevalence, characteristics, long-term outcomes and goals-of-care discussions of patients with objective indicators of life-limiting illnesses (LLIs) referred to the intensive care unit.

Design, setting and patients: A prospective, observational, cohort study of all adult inpatients referred to the ICU by the medical emergency team or by direct referral, during the period 30 August 2012 to 1 February 2013, at a tertiary teaching hospital in Australia.

Main outcome measures: Mortality, LLIs, discharge destination and documentation on goals of care in medical record.

Results: A total of 649 of 1024 patients referred to the ICU had an LLI, and only 34.4% of these patients had goals of care documented. Overall, 49.2% were admitted to the ICU, 48.4% were discharged home, and the 1-year mortality was 35.1%. The most common LLI criteria were heart disease (52.2%), chronic obstructive pulmonary disease (24.8%) and frailty (23.7%). The highest 1-year mortality was associated with pre-hospital residence in a nursing home (64.9%), dementia (63.3%), cancer (60.8%) and frailty (50.6%). Analysis of patients by clinical trajectory showed that 1-year mortality was significantly higher for patients with cancer (59.6%), combined organ failure and frailty (47.3%), frailty (43.8%) and organ failure (23.6%), compared with patients with no LLI ($P < 0.0001$).

Conclusions: A high proportion of patients referred to the ICU have an LLI, and this is associated with prolonged hospital length of stay and a high 1-year mortality, and only one-quarter have documented discussions on goals of care. Patients with cancer-related and frailty-related LLIs have the worst survival trajectories.

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The timely provision of patient-centred care for patients with life-limiting illnesses (LLIs) is vital to preserve dignity while a patient is dying,[1] but challenges remain in the critical care setting.[2-4] In the absence of documented goals of care or an advance care plan (ACP), the acute physiological deterioration that precedes death may lead to referral to a medical emergency team (MET) or the intensive care unit. This may result in the delivery of life-prolonging interventions that are non-beneficial, contrary to patient or surrogate preferences, and reduce quality of life while a patient is dying.[5-9]

The application of palliative care principles may be beneficial for these patients. There is evidence that palliative care interventions not only improve patient and family satisfaction, but also decrease the number of ICU admissions and lengths of stay for patients at high risk of death.[9-12] Current evidence is limited by the heterogeneity of populations studied, range of interventions and variable study designs.[13]

The use of objective indicators of LLI, such as the United Kingdom Gold Standards Framework (GSF)[14,15] and Supportive and Palliative Care Indicators Tool (SPICT),[16] may help practitioners identify patients with an LLI or a clinical trajectory with a high likelihood of death in the following year. These tools may also help practitioners manage discussions and set shared goals through a process that includes symptom control, psychological support, comfort care, end-of-life planning, attention to spiritual or religious issues, family and relational support and documentation.[9,15,17-23]

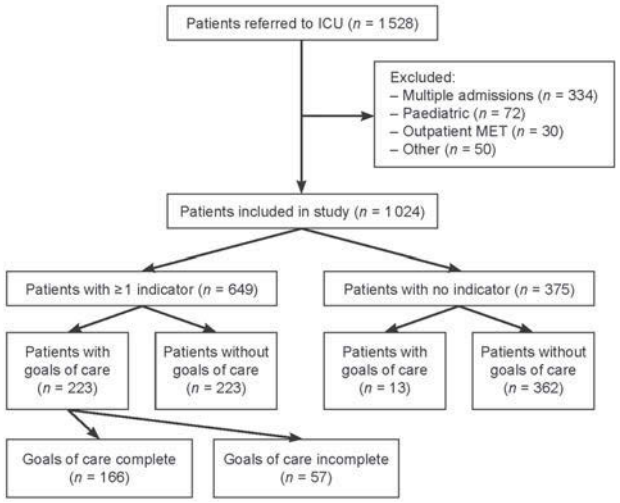
We aimed to describe the prevalence, characteristics, long-term outcomes and evidence of goals-of-care discussion of patients who had objective indicators of LLIs and were referred to a tertiary ICU.

Methods

Patients and setting

We performed a prospective, observational, cohort study in a tertiary hospital in Victoria, Australia, and obtained ethics approval from the institutional research and ethics committee before starting our study. We included adult patients referred to the ICU from 30 August 2012 to 1 February 2013. We defined referral to the ICU as admission to the ICU from an operating theatre, referral from an acute-care ward or the emergency department, or referral for assessment by the ICU-led MET service. Paediatric referrals and MET referrals from outpatient clinics or hospital visitors were excluded. We included only the initial referral for patients with multiple referrals to the ICU. Patients were identified using the ICU referral forms that are completed by doctors, and by interrogation of the ICU and hospital electronic admission databases.

Figure 1. Patient flow through study



ICU = intensive care unit. MET = medical emergency team.

Data collection

We collected demographic and clinical data and information on pre-existing advance care directives, admission diagnoses, referrals and hospital outcomes. The 1-year mortality was determined through linkage with the Australian Institute of Health and Welfare National Death Index. We defined a pre-hospital ACP as one completed in the primary care setting or documentation of treatment limitations in the patient's medical records from previous admissions.

LLI indicators and goals-of-care discussion

We developed LLI indicators from the UK GSF prognostic indicator-specific clinical indicators, general functional indicators and the SPICT.[13] The specific clinical indicators included: cancer, chronic obstructive pulmonary disease (COPD), heart failure, renal disease, neurological disease, frailty, dementia and stroke. The general functional indicators included: more than two unplanned admissions to hospital in the previous 6 months, and residence at a nursing home before hospital admission. Patients were also classified into clinical trajectory groups that were adapted from the GSF prognostic indicator guidance trajectories of cancer, organ system failure and frailty/comorbidity/dementia (see Appendix Table 1, Table 2 and Figure 1, online at cicm.org.au/Resources/Publications/Journal).

We determined and recorded the presence or absence of LLI indicators for each patient, and defined a goals-of-care discussion as the presence of the institutional treatment limitation form in the patient's current medical record, for the current hospital admission, or at the completion of the ICU referral. We defined a documented goals-of-care discussion as a document detailing a complete assessment of the competency of the patient, the seniority of the doctor conducting the discussion and the content and outcome of the discussion. A second chart reviewer blinded to the original review results reviewed a random 10% sample of treatment limitation documents to assess the level of agreement.

Outcomes

Our outcomes included the prevalence of patients referred to the ICU with objective indicators of an LLI, the occurrence and completion of goals-of-care discussions, hospital and 1-year mortality, discharge destination and analysis of factors associated with the occurrence of goals-of-care discussions and with 1-year mortality.

Statistical analysis

We performed statistical analysis with SAS, version 9.4 (SAS Institute), and compared the groups using the χ^2 test for equal proportions, or the Fisher exact test when numbers were small. We compared continuous variables with the Wilcoxon rank-sum test and report them as medians and interquartile ranges (IQRs). Analysis of factors associated with 1-year mortality and in-hospital goals-of-care discussions was performed using multivariate logistic regression, and we report results as odds ratios (ORs) and 95% confidence intervals. Multivariate models were constructed considering all available variables, using stepwise selection and backwards elimination techniques before undergoing a final assessment for clinical and biological plausibility. We performed additional sensitivity analysis of the time to death using Cox proportional hazards regression with the variables previously identified from the multivariate logistic regression model. We show survival results using a Kaplan–Meier curve, with group comparison determined using a log-rank test. A two-sided *P* value of 0.05 was considered to be statistically significant.

Results

A total of 649 of 1024 patients referred to intensive care (63.4%) had at least one LLI indicator (Figure 1). A treatment limitation was present for 223 patients with an LLI indicator (34.4%), with all goals-of-care components completed for 166 patients (25.6%).

Characteristics and outcomes

A comparison of demographics, admission diagnosis, referral source and outcomes for patients with and without LLI indicators is shown in Table 1. Patients with LLI indicators were significantly older, more often referred from medical wards, and less often referred from the emergency department. An increased proportion of patients with LLI indicators had cancer or respiratory-related admission

diagnoses, and a significantly lower proportion had trauma or non-specified medical diagnoses. In addition, a significantly lower proportion of patients with LLI indicators were admitted to the ICU, returned home after hospital discharge, and survived to hospital discharge or 1 year. Finally, their median hospital length of stay was significantly increased. Only one in 10 patients with an LLI indicator had a pre-hospital ACP, and one in three had documentation of goals of care at ICU referral.

The prevalence, characteristics and outcomes of patients in each of the LLI indicator categories are shown in Table 2. The most common LLI indicators present in patients referred to the ICU were heart failure, COPD and frailty. The proportion of admissions to the ICU after referral ranged from 8.2% in the dementia cohort to 54.6% in the heart failure cohort. The proportion of patients with a pre-hospital ACP was less than 16% in all LLI categories, and was lowest in the stroke category and highest in the renal disease category. The LLI categories with the highest 1-year mortality were pre-hospital nursing home accommodation, dementia and cancer, with the lowest 1-year mortality associated with more than two unplanned hospital admissions, heart failure and renal disease. The proportion of patients with documented goals of care ranged from 26.8% in the unplanned admissions category to 60.4% in the frailty category (Table 2).

The comparison of clinical trajectory groups is shown in the online Appendix Table 3. The group with no LLIs was younger, had the highest rates of ICU admission (66.8%) and discharge home (78.3%), and had a low 1-year mortality (7.6%). In comparison, the cancer group had the highest 1-year mortality (59.6%), 42.3% were admitted to the ICU and 45.2% returned home. A low proportion had a pre-hospital ACP (12.5%) or in-hospital treatment limitation (40.4%). The organ-failure group had a low 1-year mortality (23.6%); a high proportion were admitted to the ICU (66.2%) and 60.0% returned home. The major LLI indicator in this group was heart failure (71.8%), and this group had the highest proportion of patients referred from elective surgery (33.8%). The frailty and frailty-with-organ-failure groups were similar, with the highest proportion of in-hospital treatment limitations (56.3% and 54.7%, respectively), the lowest ICU admission rates (29.2%, 20.9%), the lowest rates of discharge home (16.7%, 27.0%) and high 1-year mortality (43.8%, 47.3%).

Table 1. Demographics, clinical characteristics and pre-hospital treatment limitation status, by presence or absence of life-limiting illness indicator

Characteristic	LLI present (*n* = 649)	LLI absent (*n* = 375)	*P*
Median age, years (IQR)	74 (62–82)	62 (47–73)	< 0.0001
Male, *n* (%)	361 (56%)	209 (44%)	0.97
Median hospital LOS at enrolment, days (IQR)	1 (0–3)	0 (0–2)	0.08
Referral source, *n* (%)			
Emergency department	100 (15.4%)	92 (24.5%)	0.0003
Medical MET	217 (33.5%)	65 (17.3%)	< 0.0001
Surgical MET	130 (20.1%)	74 (19.7%)	0.91
Operating theatre (elective)	135 (20.8%)	86 (22.9%)	0.42
Operating theatre (emergency)	52 (8.0%)	40 (10.7%)	0.15
External retrieval	15 (2.3%)	18 (4.8%)	0.03
Admission diagnosis, *n* (%)			
Cancer-related	25 (3.9%)	3 (0.8%)	0.004
Cardiac disease	47 (7.2%)	34 (9.1%)	0.3
Gastrointestinal or hepatic disease	23 (3.5%)	16 (4.3%)	0.56
Surgical (non-cardiothoracic)	182 (28.0%)	89 (23.7%)	0.13
Surgical (cardiothoracic)	106 (16.3%)	76 (20.3%)	0.11
Sepsis (pneumonia)	34 (5.2%)	15 (4.0%)	0.37
Sepsis (other)	57 (8.8%)	35 (9.3%)	0.77
Neurological disease or stroke	44 (6.9%)	16 (4.3%)	0.1
Medical (other)	59 (9.1%)	56 (14.9%)	0.004
Respiratory disease	61 (9.4%)	18 (4.8%)	0.008
Trauma	10 (1.5%)	17 (4.5%)	0.004
Pre-hospital advance care plan, *n* (%)	69 (10.6%)	11 (2.9%)	< 0.0001
Goals of care documented, *n* (%)	223 (34.4%)	13 (3.5%)	< 0.0001
Referral outcome, *n* (%)			
Admitted to ICU	319 (49.2%)	252 (67.2%)	< 0.0001
Transferred to or remained on ward	330 (50.8%)	123 (32.8%)	
Median hospital LOS, days (IQR)	9 (5–16)	7 (4–14)	0.007
Discharge destination, *n* (%)			
Home	314 (48.4%)	292 (77.9%)	< 0.0001
Nursing home	49 (7.6%)	1 (0.3%)	< 0.0001
Other hospital	52 (8.0%)	37 (9.9%)	0.31
Sub-acute care	95 (14.6%)	30 (8.0%)	0.002
Palliative care	14 (2.2%)	1 (0.3%)	0.02
Died	124 (19.1%)	14 (3.7%)	< 0.0001
1-year mortality, *n* (%)	228 (35.1%)	29 (7.7%)	< 0.0001

LLI = life-limiting illness. IQR = interquartile range. LOS = length of stay. MET = medical emergency team. ICU = intensive care unit.

Table 2. Prevalence, characteristics and outcomes of patients with life-limiting illness indicators (*n* = 649)*

Variable	Heart failure	COPD	Frailty	Neurological disease	Unplanned admissions	Renal disease	Cancer	Nursing home	Dementia	Stroke
Patients, *n* (%)	339 (52.2%)	161 (24.8%)	154 (23.7%)	127 (19.6%)	123 (19.0%)	109 (16.8%)	102 (15.7%)	74 (11.4%)	49 (7.6%)	27 (4.2%)
Median age, years (IQR)	74 (64–82)	74 (62–81)	79 (63–85)	78 (65–85)	69 (50–80)	73 (59–82)	72 (61–80)	79 (63–88)	83 (65–88)	82 (77–86)
Median hospital LOS at referral, days (IQR)	1 (0–2)	1 (0–3)	1 (0–3)	1 (0–4)	0 (0–2)	1 (0–2)	1 (0–4)	1 (0–2)	1 (0–4)	2 (1–4)
Pre-hospital advance care plan, *n* (%)	34 (10.0%)	18 (11.2%)	21 (13.6%)	16 (12.6%)	14 (11.4%)	17 (15.6%)	13 (12.7%)	11 (14.9%)	7 (14.3%)	2 (7.4%)
Goals-of-care document, *n* (%)	107 (31.6%)	73 (45.3%)	93 (60.4%)	57 (44.9%)	33 (26.8%)	42 (38.5%)	42 (41.2%)	53 (71.6%)	35 (71.4%)	11 (40.7%)
Referral source, *n* (%)										
Emergency department	43 (12.7%)	37 (23.0%)	21 (13.6%)	12 (9.4%)	24 (19.5%)	17 (15.6%)	9 (8.8%)	9 (12.2%)	1 (2.0%)	3 (11.0%)
Medical MET	98 (28.9%)	61 (37.9%)	80 (51.9%)	65 (51.2%)	41 (33.3%)	35 (32.1%)	41 (40.2%)	33 (44.6%)	27 (55.1%)	24 (88.9%)
Surgical MET	60 (17.7%)	9 (5.6%)	42 (27.3%)	30 (23.6%)	27 (22.0%)	31 (28.4%)	21 (20.6%)	29 (39.2%)	19 (38.8%)	0
Operating theatre (elective)	97 (28.6%)	22 (13.7%)	4 (2.6%)	11 (8.7%)	18 (14.6%)	13 (11.9%)	17 (16.7%)	1 (1.4%)	1 (2.0%)	0
Operating theatre (emergency)	31 (9.1%)	9 (5.6%)	6 (3.9%)	9 (7.1%)	9 (7.3%)	9 (8.3%)	12 (11.8%)	1 (1.4%)	1 (2.0%)	0
Retrieval	10 (2.9%)	6 (3.7%)	1 (0.6%)	0	4 (3.3%)	4 (3.7%)	2 (2.0%)	1 (1.4%)	0	0
ICU admission, *n* (%)	185 (54.6%)	73 (45.3%)	37 (24.0%)	39 (30.7%)	62 (50.4%)	43 (39.4%)	42 (41.2%)	12 (16.2%)	4 (8.2%)	5 (18.5%)
Outcome, *n* (%)										
Hospital mortality	62 (18.3%)	43 (26.7%)	42 (27.3%)	31 (24.4%)	15 (12.2%)	22 (20.2%)	23 (22.5%)	23 (31.1%)	18 (36.7%)	7 (25.9%)
1-year mortality	112 (33.0%)	70 (43.5%)	78 (50.6%)	55 (43.3%)	36 (29.3%)	41 (37.6%)	62 (60.8%)	48 (64.9%)	31 (63.3%)	11 (40.7%)

COPD = chronic obstructive pulmonary disease. IQR = interquartile range. LOS = length of stay. MET = medical emergency team. ICU = intensive care unit. *Patients may have had more than one life-limiting illness and may be included in more than one category.

Goals-of-care documentation

In the group of patients with documented goals of care, the process was mostly performed by registrars (67.3%), followed by residents (20.1%) and consultants (8.1%) (online Appendix Table 4). Overall, a completed goals-of-care form was documented for 166 patients (25.6%) with an LLI who were referred to the ICU.

Univariate comparison of patients with and without goals-of-care documentation is shown in the online Appendix Table 5. Patients with documentation were significantly older, more likely to have a pre-hospital ACP and be referred from medical or surgical wards, and significantly less likely to be referred directly from operating theatres. In addition, a higher proportion were admitted with a cancer-related diagnosis. Finally, patients with documentation had a significantly lower rate of admission to the ICU after referral and a significantly higher hospital and 1-year mortality. After multivariate regression analysis was performed, several factors were found to be associated with increased documentation of goals of care (Table 3).

Analysis of factors associated with 1-year mortality

A comparison of patients by mortality 1 year after ICU referral showed that non-survivors were significantly older, and more non-survivors had a pre-hospital ACP, specific admission diagnoses or an LLI indicator. A significantly higher proportion of survivors were referred from operating theatres, had an admission diagnosis of cardiothoracic surgery or were admitted to the ICU (online Appendix Table 6). After multivariate logistic regression, the factors that were independently associated with increased mortality were a non-cardiothoracic surgery referral source, any LLI indicator, the LLI cancer indicator and documentation of goals of care (Table 4).

The differences in survival according to clinical trajectory group results are shown in Figure 2. There were significant

Table 3. Multivariate analysis of factors associated with goals-of-care documentation

Effect	Unadjusted OR (95% CI)	*P*	Adjusted OR (95% CI)	*P*
ICU referral source (v elective surgery)		< 0.0001		< 0.0001
Medical MET	44.44 (16.08–122.8)		29.86 (10.5–84.89)	
Surgical MET	24.8 (8.83–69.60)		21.47| (7.38–62.48)	
Emergency department	11.26 (3.91–32.41)		12.4 (4.16–36.97)	
External retrieval	7.48 (1.77–31.55)		10.65 (2.34–48.33)	
Operating theatre (emergency)	2.47 (0.60–10.08)		2.44 (0.58–10.26)	
Any LLI indicator	14.58 (8.19–25.94)	< 0.0001	6.77 (3.57–12.80)	< 0.0001
Dementia indicator	9.63 (5.08–18.24)	< 0.0001	3.07 (1.51–6.23)	0.002
Frailty indicator	7.75 (5.36–11.21)	< 0.0001	2.59 (1.68–3.98)	< 0.0001
COPD indicator	3.56 (2.50–5.08)	< 0.0001	2.02 (1.31–3.13)	0.001
Pre-hospital advance care plan	3.41 (2.14–5.43)	< 0.0001	2.5 (1.38–4.55)	0.003
Cancer indicator	2.63 (1.72–4.02)	< 0.0001	1.98 (1.17–3.35)	0.01

OR = odds ratio. ICU = intensive care unit. MET = medical emergency team. LLI = life-limiting illness. COPD = chronic obstructive pulmonary disease.

differences in trajectories ($P < 0.0001$), with highest survival rates in patients in the group with no LLIs, and lowest survival rates in patients with cancer. The groups with frailty and combined frailty and organ failure had similar survival.

Discussion

Main findings

We performed a prospective observational study and found that a high proportion of patients referred to a tertiary ICU had objective indicators of LLIs and associated prolonged hospital lengths of stay, loss of independence and high 1-year mortality. We also found that only one-quarter had documented evidence of goals-of-care discussions. Stratification of patients by type of LLI showed distinct survival trajectories, with the cancer-related and frailty-related groups associated with worse survival.

Relationship to previous studies

We found that a large proportion of patients referred to the ICU had objective indicators of an LLI, and that most deaths in the first year after referral to the ICU occurred in these patients. The intersection of life-limiting disease and intensive care is well described, with ICU admission before death estimated to occur in 5.1% of all deaths in England and 17.2% of all deaths in the United States.[2] About 2000 patients per year are admitted to Australian and New Zealand ICUs with treatment limitations already in place.[24] Also, for up to 20% of Australian and New Zealand hospital deaths, the patients are reviewed by an MET service before they die,[25] and in about one-quarter of MET calls, the patient has an existing not-for-resuscitation order.[26]

The use of objective indicators for LLIs may improve the identification of patients whose clinical trajectory of disease and disability is approaching death. In our study, the presence of an LLI indicator derived from established palliative care tools was strongly associated with 1-year mortality. In addition, the stratification of patients into clinical trajectory groups showed distinct survival trajectories for patients with cancer, frailty, organ failure and no LLI.

The prevalence and outcomes of patients with GSF criteria have previously been reported for hospital populations but not for ICU populations. An Australian study of hospital inpatients reported the presence of GSF criteria in 27.3% of patients, with an associated 50.3% 1-year mortality.[3] In New Zealand inpatients, 19.8% had GSF criteria and two-thirds died within 6 months of admission.[27] A cross-sectional survey of two UK hospitals found that 36.0% of inpatients had GSF criteria.[15] In the critical care setting, previous studies have reported the use of criteria to identify patients at high risk of dying. Criteria included LLI,[10,28] age,[9,29] cancer[30] and checklists combining acute physiological and chronic disease criteria.[31] An Australian study reported that 39.6% of patients referred to an MET team had an LLI, with an associated 41.7% mortality at 3 months.[28] The use of a set of ICU-based primary criteria for palliative consultation identified 13.8% to 84% of ICU admissions as having a palliative care trigger, with a 39.7% to 59.5% hospital mortality.[32,33] The criteria, when used by a proactive palliative care ICU rounding team, resulted in an increase in family meetings and reduced ICU and hospital lengths of stay, and were associated with a 35% 90-day mortality.[34]

The reduced survival associated with clinical trajectories of cancer, frailty and organ failure is an important finding of this study and adds to the existing literature. A recent observational study of very old patients needing more than 24 hours of ICU support found that only one-quarter of patients were alive and recovered to pre-hospital function at 1 year, and that frailty was a more significant independent predictor of long-term outcomes than age, illness severity or comorbidity.[29] In addition, frailty was associated with reduced health-related quality of life and functional dependence, and disability outcomes in a cohort of critically ill patients older

Table 4. Multivariate analysis of factors associated with 1-year mortality

Factor	Unadjusted OR (95% CI)	*P*	Adjusted OR (95% CI)	*P*	Adjusted HR (95% CI)	*P*
Admission category (v cardiothoracic surgery)		< 0.0001		0.03		0.02
Cancer-related	29.70 (10.80–81.72)		3.19 (0.91–11.17)		3.41 (1.10–10.57)	
Pneumonia	14.41 (6.00–34.65)		4.18 (1.53–11.44)		4.01 (1.41–11.35)	
Gastrointestinal	13.37 (5.3–33.73)		4.96 (1.69–14.49)		6.67 (2.30–19.33)	
Respiratory	11.77 (5.24–26.44)		4.54 (1.88–10.97)		4.39 (1.60–12.01)	
Neurology	8.69 (3.67–20.58)		3.24 (1.23–8.53)		3.87 (1.35–11.12)	
Cardiac disease	7.62 (3.34–17.41)		5.34 (2.21–12.86)		6.51 (2.40–17.66)	
Surgery (non-cardiothoracic)	6.69 (3.25–13.79)		2.83 (1.31–6.10)		4.79 (1.90–12.08)	
Other sepsis	6.41 (2.82–14.54)		2.33 (0.94–5.78)		2.88 (1.02–8.14)	
Other medical	5.61 (2.52–12.49)		2.79 (1.16–6.69)		3.26 (1.18–9.03)	
Trauma	2.40 (0.61–9.50)		1.94 (0.43–8.71)		3.23 (0.62–16.76)	
Any life-limiting illness indicator	6.46 (4.28–9.75)	< 0.0001	2.43 (1.51–3.92)	0.0003	2.00 (1.25–3.19)	0.004
Cancer indicator	5.78 (3.77–8.86)	< 0.0001	4.13 (2.35–7.26)	< 0.0001	2.64 (1.77–3.93)	< 0.0001
Goals of care documented	13.26 (9.43–18.65)	< 0.0001	2.89 (1.37–6.10)	0.01	1.77 (0.84–3.74)	0.13

OR = odds ratio. HR = hazard ratio.

than 50 years.[35] A series of observational studies relating to a longitudinal study of decedents from a community cohort of older people reported distinct trajectories of disability in the year before death, with frailty, organ failure, cancer, "another condition" and advanced dementia the most common conditions leading to death. There was significant heterogeneity in the distribution of disability trajectory in the year before death for these conditions, except for dementia and sudden death in patients with no disability, although acute hospital admissions strongly contributed to the disabling process.[36,37] In addition, it was found that the pre-ICU functional trajectory independently affected the outcomes of patients admitted to the ICU.[38]

In our study, only one-third of patients with an LLI had documented goals of care at referral to the ICU. There was evidence of patient involvement in the goals-of-care discussions in only one-quarter of cases. This is consistent with the existing evidence on MET teams and patients with LLIs, with treatment limitations instituted in up to 30.8% of MET calls.[39] Treatment limitation documentation frequently occurs after an MET referral, suggesting that activation of MET teams leads to modification of therapeutic goals in the face of deterioration.[28,40] A patient-centred approach, including discussion of the patient's goals and values, has been shown to increase adherence to management, reduce morbidity, improve quality of life and reduce use of diagnostic tests.[41]

Strengths and limitations

Ours is the first study to describe both the prevalence and long-term outcomes of patients with objective indicators of an LLI referred to an ICU. Our study is important because it provides information about the validity of these indicators in a critical care population. We also describe the presence or absence of discussions about goals of care and the factors associated with such discussions. This provides valuable information for future interventions designed to improve the delivery of patient-centred care in this population.

There are some limitations to our study. We did not record the reasons for ICU refusal or admission, the presence or absence of reversible processes that may have been treated at ICU referral, the reasons why discussions on goals of care were not documented, or details of death, because our objective was to assess the evidence for patient-centred care in a high-risk population, rather than provide a detailed description of disease-centred care. We did not measure patient-centred outcomes such as quality of care or experience, but there is existing evidence clearly showing improved outcomes associated with better communication and shared decision making for patients with LLIs.[1,4,13,42]

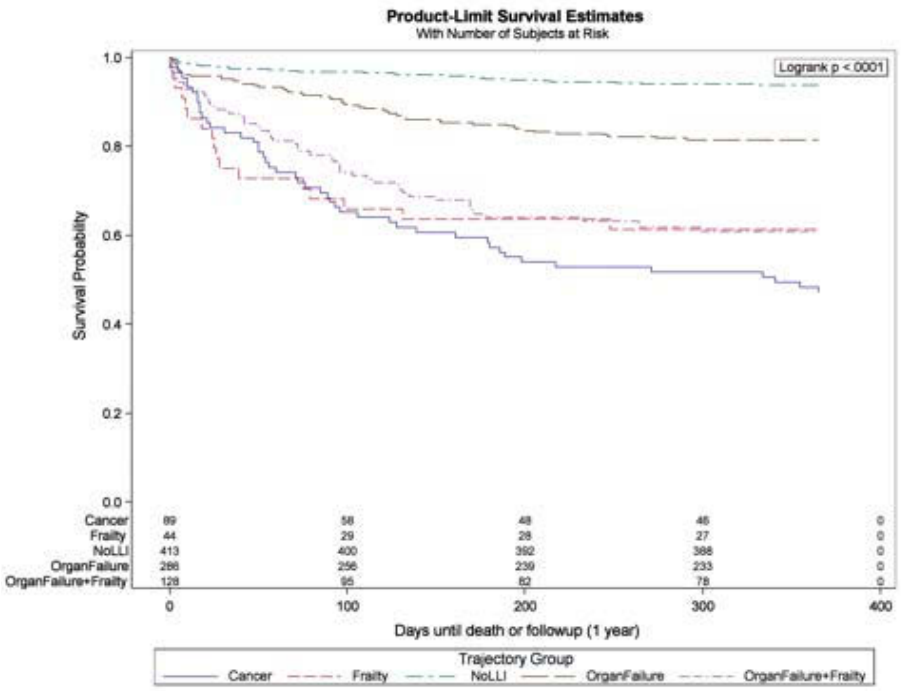
Conclusion

A high proportion of patients referred to the ICU had objective criteria of an LLI, with prolonged hospital care and high 1-year mortality. Only one-quarter of patients had evidence of discussion of goals of care at the time of referral to the ICU, a finding that supports the need for programs designed to improve patient-centred care in this high-risk population.

Competing interests

None declared.

Figure 2. Product-limit survival estimates, with number of subjects at risk



NoLLI = no life-limiting illness.

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